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# A National Examination of Publically Funded Pediatric Palliative Care Programs and Hospitalization Characteristics

By

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**Abstract**

**Background:** Prior to enactment of the Affordable Care Act in 2010 few states had pediatric palliative care. Literature suggests that adult palliative care services result in cost savings, but little literature provides evidence about the effect of pediatric palliative care on cost, and no literature as yet compares costs in states with and without pediatric palliative care programs.

**Objective:** To investigate differences in hospitalization characteristics between states with and without pediatric palliative care programs.

**Design:** I used the 2009 Healthcare Cost and Utilization Project Kids' Inpatient Database (Agency for Healthcare Research and Quality) to determine total hospital charges, length of stay, and number of procedures associated with all in-hospital pediatric deaths. I compared median values of states with and without pediatric palliative care and regressed presence of palliative care on all variables to examine total hospital charges. I further adjusted the model for length of stay and number of procedures and I repeated the analysis with an adjustment for the presence of a Diagnosis Related Group for neuromuscular disorder, one of the most common diagnoses in pediatric palliative care programs.

**Results:** I found that patients who died in hospital in states with pediatric palliative care programs had higher hospital charges, longer hospital stays, and more procedures during their hospitalization. The difference in charges closed dramatically for patients with neuromuscular disorders.

**Conclusion:** States with pediatric palliative care programs have higher hospital-based health care utilization over all, but state palliative care programs are in their infancy, and in states with such programs, costs associated with conditions amenable to palliative care do not significantly differ from median costs. These findings suggest that implementing palliative care programs may not cause significantly higher costs for patients who most commonly receive palliative care, and it is possible that the early effect of pediatric palliative care programs on hospital charges varies by diagnosis.

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## Introduction

Pediatric palliative care is a relative newcomer to the field of medicine. While several large organizations, such as the World Health Organization (WHO) (http://www.who.int/cancer/palliative/definition/en/) and the American Academy of Pediatrics (AAP) (American Academy of Pediatrics, 2000), have led the calls since the turn of the 21st century for more access to palliative care for children, the American health care system did not respond to the challenge for an entire decade. Pediatric palliative care was not required for patients receiving government-sponsored insurance until the passage of the Affordable Care Act in 2010 (PL 111-148). Almost all states required that children waive their right to curative treatment and be in the last six months of their life to receive hospice care; they virtually all denied the provision of palliative care to their pediatric population. In this paper, I will explain the background of pediatric palliative care in the United States. Additionally, I will examine the differences in hospital charges, length of stay, and number of procedures during hospitalizations that resulted in pediatric deaths between states that did and states that did not have pediatric palliative care programs in 2009.

## Background

The concept of hospice care started in the United Kingdom over 50 years ago, and it did not spread to the United States until the first hospice center was established in Connecticut in 1974 (Emanuel and Emanuel, 1998). Since that time, hospice care has evolved into comprehensive palliative care, and the health care system has come to embrace the concept of end-of-life care. By the nature of medical subspecialty evolution, pediatric subspecialties can lag behind adult medicine subspecialties in some innovations, and palliative care is no different. Children succumb to terminal illnesses at a lower rate than do adults; however, they have always faced lethal congenital abnormalities, fatal diseases, and traumatic injury and death. Despite the fact that children have always faced life-limiting conditions, some of the first calls for

a more organized method of delivery of palliative care for children did not come until the mid-1990s. In 1996, Frager published a call for better organization of pediatric palliative care in the Journal of Palliative Care. He called for linking children and families with palliative care resources early after the diagnosis of a terminal illness for maximal emotional, spiritual, and physical support (Frager, 1996).

In the years following Frager's paper, other organizations put out a call for better pediatric palliative care services and each attempted to define what those services should entail. The WHO was one of the first large groups to define pediatric palliative care and outline the important elements required to care for a child with a life-threatening illness and his or her family. They reinforce the idea that palliative care in pediatrics should start at the time of diagnosis of a life-limiting illness, and practitioners who treat the children should work to care for their physical, psychological, and social problems (http://www.who.int/cancer/palliative/definition/en/). The WHO places their palliative care guidelines under their cancer program. The oncology world and palliative care have often worked hand-in-hand, with the International Society of Paediatric Oncology (SIOP) publishing one of the first organizational guidelines for treating children with a terminal illness. Although their guidelines are centered on caring for children with cancer, they outline several principles that apply to caring for all terminally ill children and their families (Masera, Spinetta, Jankovic, et al., 1999).

Shortly after SIOP published its manuscript defining the key elements involved in the palliative care of children, the AAP released a joint official statement from the Committee on Bioethics and the Committee on Hospital Care establishing principles of palliative care for children who face life-limiting conditions. This statement describes palliative care as a way to enhance the quality of life of a dying child through "relief of symptoms (e.g., pain, dyspnea) and conditions (e.g. loneliness) that cause distress and detract from the child's enjoyment of life;" it also argues that palliative care should address the bereavement of the entire family (American

Academy of Pediatrics, 2000). In its statement, the AAP defines the key elements and minimum standards of a pediatric palliative care program, integration of palliative and curative treatment, developing a palliative plan, the contrast between palliation and hastening death, and barriers to palliative care (American Academy of Pediatrics, 2000). Since the initial release of the statement in 2000, the AAP has reaffirmed its position on pediatric palliative care twice, most recently in 2012 (American Academy of Pediatrics, 2012).

In 2010, pediatric deaths (defined as deaths of those less than 20 years old) accounted for 45,068 of the almost 2.5 million deaths in the United States (http://www.cdc.gov/nchs/data/nvsr/nvsr61/nvsr61_04.pdf), and trends in the data show that children with complex chronic conditions are living longer (Friebert, 2009). The Affordable Care Act (ACA) enacted in 2010 includes provisions requiring "concurrent care" for children. Concurrent care means that while receiving hospice services pediatric patients can also obtain treatment and curative services related to their underlying life-limiting condition. Section 2302 of the ACA says that acceptance of hospice care in a pediatric patient on Medicaid does not waive the rights of that child to receive treatment for a terminal illness, with similar wording added to the CHIP legislation (PL 111-148). This policy change required subsequent changes in state policy governing payment for the care of children with life-limiting illnesses, since before ACA enactment, most states had refused to pay for curative therapy for children in hospice care.

Pre-ACA, funding for pediatric palliative care was complex. In most states, children on Medicaid waived their right to life-prolonging or curative therapy once they entered hospice care. States had the option of providing pediatric palliative care, and some found ways to provide true palliative care to their pediatric population. States could apply for a waiver to receive permission from the federal government to provide benefits not normally provided by Medicaid. One mechanism is a Section 1915 waiver, also known as a Home and Community-Based Services waiver, allows state Medicaid to reimburse for services received in the home and other community settings instead of an institutionalized environment

(http://hdwg.org/sites/default/files/palliativecare.pdf). Another state payment mechanism was through state amendment or change to the state's own Medicaid legislation (http://www.nhpco.org/sites/default/files/public/ChiPPS/Continuum_Briefing.pdf). Before the federal legislation in 2010, very few states had taken the initiative to pro-actively provide palliative care to their pediatric population.

Palliative care has many benefits, and one of the main benefits of palliative care is improved quality of life and patient satisfaction. Caregivers conclude that patients and their families who have end-of-life discussions with their physicians and care teams have an improved quality of life (Zhang, B., Wright, A.A, Huskamp, H.A., 2009). The interdisciplinary nature of the care team helps patients who participate in palliative care achieve better pain control and symptom management (Meier, D.E., Brawley, O.W., 2011). Palliative care may even prolong survival. A recent study of those with metastatic non-small cell lung cancer who entered early palliative care found these patients lived a median two months longer than did those who did not receive palliative care (Temel, J.S., Greer, J.A., Muzikansky, A., 2010).

In addition to improved quality of life and potential improved survival, several studies in the adult medical literature show that palliative care reduces long term spending on health care. The financing of the American health care system is historically grounded in fee-for-service payments for procedures. Palliative care physicians and care teams are more likely to provide education, counseling, and support than invasive procedures. They help patients and families weigh the pros and cons of various treatment options and allow truly informed decisions about which of those options the patient would like to pursue. Palliative care has been a conundrum in the traditional health financing model, requiring palliative care providers and payers alike to reconceptualize its "value". One strategy is to promote palliative care teams' ability to save payers money by "cost avoidance." Cost avoidance is the idea that a patient receiving good palliative care will be less likely to incur expensive, invasive, and often futile services (Smith, T.J., Cassell, J.B., 2009). Kelley, Deb, Du, et al. show that Medicare can save up to $6,430 per

patient enrolled in hospice care for at least 15 days prior to death (Kelley, A.S., Deb, P., Du, Q., et al., 2013). Another group provides an analysis showing that recipients of palliative care saved $1,696 per admission when discharged from the hospital alive and $4,908 in savings per admission if they died during the hospitalization (Morrison, R.S., Penrod, J.D, Cassel, J.B., 2008). Estimates suggest that reductions in Medicaid hospital spending in New York state alone could reach up to $252 million if all hospitals over 150 beds had palliative care teams (Morrison, R.S., Dietrich, J., Ladwig, S., 2011).

The literature in the pediatric population examining cost savings and palliative care is scarce (See Appendix A). A cost analysis of California's Partners for Children, the state's public pediatric palliative care program, shows that since its inception, the program has both improved the quality of health care provided to the participants and saved the state money. Those participating in the program have seen a reduction in their health care costs of 11 percent. This drop in costs is mostly attributed to a reduction in inpatient hospitalization costs by cutting the number of days in the hospital by one-third. Participants used more outpatient services, but overall, these services were much less expensive than are in-hospital charges. The lower spending did not come by sacrificing quality of care, as 97 percent of the families surveyed within the program said they were happy with the care and would recommend the program to family and friends (Gans, Kiminski, Roby, et al., 2012).

Florida is another state that has examined its pediatric palliative care program to evaluate quality and costs. Their program, titled Florida's Partners in Care: Together for Kids (PIC:TFK) has cared for 615 children and their families since its inception. The program is centered in six different sites around the state that have hospice centers and nurse care coordinators. In addition to treatment for their underlying illness, when appropriate, the patients and their families receive support counseling, personal care help, respite care, nursing care, music therapy, art therapy, and play therapy. A survey showed 93 to 100 percent of parents were satisfied with the services their child and family were receiving. In addition to improved

quality of life for the families involved in the program, Florida's evaluation estimates a savings in the cost of all services of $10,000 per year per child in the first three years after inception (http://ahca.myflorida.com/Medicaid/quality_management/mrp/contracts/med052/final_annual_pic_report_february_2009.pdf).

While few states prior to the passage of the ACA had state-funded pediatric palliative care programs, even fewer have published evaluations of the quality and cost of their program. Florida and California claim their programs overall have resulted in cost savings while caring for children needing palliative care (Gans, Kiminski, Roby, et al., 2012; (http://ahca.myflorida.com/Medicaid/quality_management/mrp/contracts/med052/final_annual_pic_report_february_2009.pdf); however, Massachusetts has not published a cost evaluation of its program (Bona, Bates, Wolfe, 2011). Furthermore, there is no evaluation in the literature comparing the medical charges of states that do and states that do not provide pediatric palliative care. In this paper, I attempt to determine differences between states who have and do not have publically funded pediatric palliative care programs via an examination of their hospitalization characteristics prior to the implementation of the ACA in 2010.

## Methods

I used the data available in the 2009 edition of the Healthcare Cost Utilization Project (HCUP) Kids' Inpatient Database (KID). I searched for all patients who had died during their hospitalization in the database. The 2009 KID data include information on 8,855 pediatric (but not neonatal) deaths. I excluded all neonates, because most neonates who die during their initial hospitalization after birth would not have received services from a pediatric palliative care program. *Perinatal* palliative care programs consisting of maternal-fetal medicine physicians, neonatologists, and pediatricians more frequently do the counseling and provide the palliative services in this population than do *pediatric* palliative care programs. I gave each state a score for its pediatric palliative care program as it existed in 2009 (See Table 1). I assigned scores

ranging from zero to three based on three questions: Was there a state funded pediatric palliative care program in 2009? Was the program available to the entire state at that time? Is information about the program easily accessible? A "yes" for any question equaled one point. See Appendix B for a more detailed account of how each category was defined and scored.

The main outcome was total charge for the hospitalization in which the patient died, and secondary outcomes were number of procedures in, and length of stay of, the last hospitalization. The exposure was the state's pediatric palliative care score. I stratified the observations by state and calculated basic statistics of maximum, minimum, median, and mean hospital charges. See Table 2 for the specific values for each state. I regressed total charges, number of procedures, and length of stay on the state palliative care score was the primary independent variable for all pediatric (non-neonatal) in-hospital deaths in each state but, as is obvious in Table 1, the distribution of state scores for quality of pediatric palliative care program was heavily skewed, with a majority of states receiving a score of zero. Only one state, Massachusetts, received a perfect score of three, severely distorting the distribution of the independent variable.

I recoded the independent variable to a dummy where 1 equals any semblance of a pediatric palliative care program, and then used this categorical variable to discriminate among median total hospitalization charges. Because even the recoded variable did not have a normal distribution, I used the Wilcoxon Rank Sum test of differences in charges, and repeated it for number of procedures and median lengths of stay.

I performed a third analysis of the data to examine whether number of pediatric inpatient palliative care programs within a state played a bigger role in influencing total hospital charges than did a state's legislated pediatric palliative care program. Using the publically available information from the Center to Advance Palliative Care (CAPC), I tabulated the number of inpatient pediatric palliative care programs per state (See Table 1) (getpalliativecare.org). I then performed a Spearman's Correlation to determine if there was a statistically significant

relationship between the number of inpatient pediatric palliative care in each state and the median total hospital charges, median length of hospital stay, and median number of procedures performed (Table 5).

Fuedtner and colleagues have established that the most common diagnoses in pediatric palliative care programs fall in to the categories of either genetic/congenital conditions or neuromuscular conditions (e.g. Fuedtner, Kang, Hexem, et al., 2011). One of the variables available in the HCUP 2009 KID database is Diagnosis Related Group (DRG). In the 24th version of DRG used for the 2009 data, no DRG for congenital or genetic condition exists (http://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/AcuteInpatientPPS/Acute-Inpatient-Files-for-Download-Items/CMS1247844.html), but the data contain several DRG codes for medical neuromuscular conditions (ranging from neuromuscular cancers to dystrophies, spinal pathologies, and other such conditions). Neuromuscular conditions are thought to be responsible for 3 to 4% of all childhood deaths, but 18% of the deaths of children with complex chronic conditions (Feudtner, Feinstine, Satchell et al. 2007). I thus created a new dummy variable by collapsing all DRG codes consistent with a neuromuscular condition into value 1, with the remaining DRGs taking the value 0, to distinguish deaths associated with these neuromuscular conditions. I then regressed total charges on presence of a state pediatric palliative care program, length of stay, and number of procedures, and then repeated the regression, adding the neuromuscular condition dummy to the equation. I used that model to calculate adjusted means to determine the difference and interaction between both patients with and without neuromuscular diseases in and out of states with pediatric palliative care programs.

In a final analysis of the data, I examined only the patients who died with a DRG consistent with having a neuromuscular condition. In order to determine if being in a state with a palliative care program changed the hospital costs for this population alone, I fit a regression model with total hospital charges as the final outcome. The model was adjusted for presence of palliative care, length of hospital stay, and number of procedures. Using this model in only

patients with neuromuscular disease, I calculated adjusted mean hospital charges based on the presence or absence of a state pediatric palliative care program. The results of all these analyses appear below.

## Results

Regressing total hospital charges on the state palliative care program score produces a statistically significant beta coefficient (Table 3), but a graphic data display (Figure 1) shows a regression line with very shallow slope and poor fit to the data. In addition, the coefficient of determination is only 0.0062, which is consistent with the regression not being a good model to fit the data. The statistical significance is likely due to the large sample size of the study, meaning that there is no practical significance to the statistical finding. The same results are true of the regression model for both length of stay and number of procedures in relationship to state scores (Table 3 and Figures 2&3): although they are statistically significant, the clinical significance seems to be minimal.

After collapsing the state scores into two categories, the observations in each category were 34 in the group with no pediatric palliative care program and seven in the group with a program (because the KID data do not include every state, and because I am precluded from reporting data on states with fewer than 10 cases). The results of the non-parametric testing are available in Table 4. There was no statistically significant difference between groups in the minimum total charges, minimum length of stay, minimum number of procedures, or maximum length of stay. The total hospital charges are both statistically and practically significantly different; the states with pediatric palliative care programs have higher hospital charges. They also have longer length of stays and more procedures performed during the hospitalizations.

The results of the Spearman's rank correlation examining the relationship between the state's number of inpatient pediatric palliative care programs and median hospital charge, length of stay, and number of procedures are available in Table 5. The number of inpatient pediatric

palliative care programs is positively but rather counterintuitively correlated with the median total hospital charge, median length of stay, and median number of procedures in each state, and each correlation is statistically significant. These trends are graphically illustrated in Figures 4 – 6.

In the next phase of the analysis, I wanted to determine if lower total hospital charges were associated with states with pediatric palliative care legislation in a patient population with a disease process amenable to palliative care. Descriptive data from the newly created variable defining whether or not the diagnosis was related to a neuromuscular condition showed that the mean charges for those with neuromuscular disease were lower than for those without neuromuscular disease (Table 6). The results of multiple regression models – presence of pediatric care, length of stay, and number of procedures, and then repeated with the addition of the neuromuscular DRG dummy can be found in Table 7. The beta coefficients of the two models show some variation, but we can get a better look by creating a 2 by 2 design of presence or absence of palliative care programs, and presence or absence of a neuromuscular DRG at the time of death (but including all other independent variables in all four analyses). The adjusted means in the 2 by 2 design as displayed on Table 8. The four different means are significantly different from each other (p-value < 0.001), and this approach to the data shows that the cost difference among those with a neuromuscular disease in states with a pediatric palliative care are significantly lower than in states without a strong pediatric palliative care presence. Another way to look at this is to scrutinize only the hospitalizations of children with neuromuscular disorders. Running the regression equation for just this subset of patients repeats this pattern, strongly explaining variance ($R^2 = 0.5832$, $p < .001$), and showing that adjusted mean costs, displayed in Table 9, are not significantly different by presence of palliative care program.

## Discussion

The KID data permit an analysis of in-patient deaths, costs of hospitalization (measured by charges), and the presence of a palliative care program, but the analysis produces apparently counterintuitive results. States that had any features of a state funded pediatric palliative care program had higher median hospital charges for pediatric patients who died during their hospital stay in 2009. In addition, the patients in states with pediatric palliative care had longer hospital stays and experienced more procedures. The investigation into a correlation between the number of inpatient pediatric palliative care programs in a state and hospital charges, length of stay, and number of procedures also showed a positive association. When total hospital charges are adjusted for patients with a set of disease processes commonly amenable to palliative care and the presence of a state pediatric palliative care program, charges increase only slightly, but the difference in cost falls for this population, and there is no statistical difference in the adjusted mean total hospital charges between states with and without palliative care programs who are caring for these patients. These findings suggest that states with pediatric palliative care programs prior to 2009 had higher in-hospital health care utilization. They also show that implementing pediatric palliative care programs may not cause significantly higher costs for patients who most commonly receive palliative care. It is also possible that the effect of pediatric palliative care programs on hospital charges varies by diagnosis.

One explanation for this failure to demonstrate lower costs in states with pediatric palliative care programs is geography. Families with children who are suffering with life-limiting illnesses are not confined by state borders as they search for care. They may opt to leave their home state to pursue care in a facility that has more experience taking care of rare or complex illnesses. States that care for more of these children will have both higher hospital charges and more pediatric deaths, and states that offer pediatric palliative care may take care of more pediatric patients with complex illnesses. In order to explore this possibility, I plotted the median

hospital charges against the total number of pediatric deaths for each state (See Figure 7). There appeared to be a positive correlation, and a linear regression produced a significant beta-coefficient and a well-fitting model. These data show higher hospital charges follow higher numbers of pediatric deaths. States with higher charges are likely offering more pediatric services, and pediatric palliative care is likely one of these services.

Another explanation for these findings could be timing. For the purposes of scoring state's pediatric palliative care, I used legislation as of 2009, to coincide with the latest year of available KID data, 2009. Some of the states with pediatric palliative care programs may have not had time to see any savings from the institution of their programs. For example, the legislation that established California's program was passed in 2008 but the program did not start full implementation until 2010 (Gans, Kiminski, Roby, et al., 2012). Another state with high hospital charges is the state of Massachusetts. Its pediatric palliative care program was started after the 2006 health reform in that state (Keim-Malpass, Hart, Mill, 2013). Pre- and post-program development cost analyses would more accurately reflect if and when the programs began to generate cost savings. Our one snapshot in time may not accurately reflect changes that have occurred before and after palliative care program implementation.

Finally, states with pediatric palliative care programs may have started the programs in an attempt to curb already high spending. As demonstrated in Table 10, five of the seven states with pediatric palliative care programs are in the highest quartile of median hospital costs. These states, with consistently higher health care costs, may have wanted to find a way to lower spending. Their pediatric palliative care programs may actually have brought even higher charges down, a hypothesis that could be tested with time series analysis on longitudinal data.

One large assumption in this analysis is our expectation that existence of a legislative program parallels use of that program. This may not be the case. To help further delineate this interaction, I wanted to determine if there was a correlation between the number of inpatient pediatric palliative care programs in a state and charges, length of stay, and number of

procedures. Unfortunately, KID data do not contain information on which hospitals in the database provide inpatient palliative care, nor do the data include a designation for an admission for hospice or palliative care. The lack of ability to distinguish which admissions, if any, were for hospice or palliative care prevents accounting for those costs. CAPC maintains a public database on their website (getpalliativecare.org) containing hospitals in the United States with inpatient palliative care programs, and they note which programs accept pediatric patients. I used this database to generate a statistical analysis showing a positive correlation between the number programs per state and hospital charges, length of stay, and number of procedures (Table 5 and Figures 4-6), but the hospitals in the HCUP KID database and those in the CAPC's may not be the same hospitals (hospitals in the HCUP KID databased are de-identified). Additionally, the data from CAPC are from 2012, a different policy climate, post-ACA implementation. The rise in hospital pediatric palliative care programs beyond the number of states with their own legislation may reflect the federal policy change.

According to Gans, Kominski, Roby, et al., the largest proportion of cost savings from California's pediatric palliative care program resulted from avoidance of hospitalizations. Inpatient costs for services are higher than outpatient costs for similar services (Belasco, Danz, Drill, et al.; 2000), so the state programs save money if they keep the participants out of the hospital. The HCUP KID database is based on hospitalizations, so I am unable to account for any health care cost savings that states experienced by keeping their palliative care patients out of the hospital.

## Conclusion

This paper is the first to examine health care costs relative to pediatric palliative care programs nationwide. While it does not show that publically funded pediatric palliative care programs lead to lower hospital charges, shorter lengths of stay, or fewer procedures among children who died during their hospitalization in 2009, it does show that the cost difference drops among those with illnesses that are amenable to and frequently represented in palliative care programs. The interaction between pediatric palliative care and cost is complex and does not appear, yet, to have the direct relationships apparent in the adult population. The findings within the neuromuscular disease group suggest that pediatric palliative care's effect on hospital costs may vary by diagnosis. Children involved in palliative care programs may undergo more procedures for palliation (i.e. gastrostomy tubes for feeds), and the palliative care programs may not result solely in procedure avoidance, as has been documented in adults.

The number of states with pediatric palliative care programs in 2009 compared to the number of inpatient pediatric palliative care programs from CAPC in 2012 shows a trend toward more palliative services offered. After the implementation of Section 2302 of the ACA in 2010, all states are required to offer palliative care to their Medicaid pediatric population. Does the uptick in programs reflect a diffusion of federal policy? Or does it reflect the progressive emergence of the field of pediatric palliative care? Watching the trends in health care utilization and expenses as more states define how they will offer these services may offer insight into the most cost-effective manner in which to institute the state-level policies. Further questions revolve around the future evolution of pediatric palliative care. Will state policies and programs develop to provide these services, like the Massachusetts model? Or, will hospitals lead the charge by developing their own programs to increase their reimbursement now that the services are required by federal law?

Pediatric palliative care is an emerging field with significant traction behind it driven by the Affordable Care Act and the advocacy of a variety of groups, from the AAP to family groups.

The service will, clearly, grow. The clinical, patient advocacy, and scholarly communities can and should focus on finding the most efficient ways to deliver palliative services, maintain a high quality of care, and improve the stewardship of resources.

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**Table 1- Pediatric Palliative Care Program Score for Each State**

| State | Peds PC State Legislation in 2009 | Covers the Entire State | Easily Accessible | Total Score | Number of Inpatient Peds PC in 2012 |
|---|---|---|---|---|---|
| Alabama | 0 | 0 | 0 | 0 | 3 |
| Alaska | 0 | 0 | 0 | 0 | 1 |
| Arizona | 0 | 0 | 0 | 0 | 5 |
| Arkansas | 0 | 0 | 0 | 0 | 2 |
| California | 1 | 0 | 1 | 2 | 20 |
| Colorado | 1 | 0 | 0 | 1 | 2 |
| Connecticut | 0 | 0 | 0 | 0 | 2 |
| Delaware | 0 | 0 | 0 | 0 | 2 |
| Florida | 1 | 0 | 1 | 2 | 10 |
| Georgia | 0 | 0 | 0 | 0 | 5 |
| Hawaii | 0 | 0 | 0 | 0 | 0 |
| Iowa | 0 | 0 | 0 | 0 | 3 |
| Idaho | 0 | 0 | 0 | 0 | 1 |
| Illinois | 0 | 0 | 0 | 0 | 8 |
| Indiana | 0 | 0 | 0 | 0 | 2 |
| Kansas | 0 | 0 | 0 | 0 | 1 |
| Kentucky | 0 | 0 | 0 | 0 | 4 |
| Louisiana | 0 | 0 | 0 | 0 | 1 |
| Massachusetts | 1 | 1 | 1 | 3 | 3 |
| Maryland | 0 | 0 | 0 | 0 | 1 |
| Maine | 0 | 0 | 0 | 0 | 1 |
| Michigan | 1 | 0 | 1 | 2 | 6 |
| Minnesota | 0 | 0 | 0 | 0 | 8 |
| Missouri | 0 | 0 | 0 | 0 | 6 |
| Mississippi | 0 | 0 | 0 | 0 | 3 |
| Montana | 0 | 0 | 0 | 0 | 3 |
| Nebraska | 0 | 0 | 0 | 0 | 5 |
| Nevada | 0 | 0 | 0 | 0 | 1 |
| New Hampshire | 0 | 0 | 0 | 0 | 1 |
| New Jersey | 0 | 0 | 0 | 0 | 7 |
| New Mexico | 0 | 0 | 0 | 0 | 1 |
| New York | 1 | 0 | 0 | 1 | 17 |
| North Carolina | 0 | 0 | 0 | 0 | 9 |
| North Dakota | 0 | 0 | 0 | 0 | 2 |
| Ohio | 0 | 0 | 0 | 0 | 7 |
| Oklahoma | 0 | 0 | 0 | 0 | 4 |

| | | | | | |
|---|---|---|---|---|---|
| Oregon | 0 | 0 | 0 | 0 | 7 |
| Pennsylvania | 0 | 0 | 0 | 0 | 6 |
| Rhode Island | 0 | 0 | 0 | 0 | 0 |
| South Carolina | 0 | 0 | 0 | 0 | 4 |
| South Dakota | 0 | 0 | 0 | 0 | 4 |
| Tennessee | 0 | 0 | 0 | 0 | 4 |
| Texas | 0 | 0 | 0 | 0 | 6 |
| Utah | 0 | 0 | 0 | 0 | 2 |
| Virginia | 0 | 0 | 0 | 0 | 5 |
| Vermont | 0 | 0 | 0 | 0 | 2 |
| Washington | 1 | 0 | 0 | 1 | 6 |
| West Virginia | 0 | 0 | 0 | 0 | 2 |
| Wisconsin | 0 | 0 | 0 | 0 | 7 |
| Wyoming | 0 | 0 | 0 | 0 | 1 |

Key: PC- Palliative care

**Table 2- Descriptive Data for Each State Used in the Analysis**

| State | Number of Pediatric Deaths | Minimum Total Charge ($) | Maximum Total Charge ($) | Median ($) | Mean Total Charge ($) |
|---|---|---|---|---|---|
| AR | 121 | 501 | 1482007 | 59100.5 | 186356.5 |
| AZ | 217 | 3557 | 1402725 | 104482 | 221139.8 |
| CA | 1357 | 380 | 1498938 | 112927 | 234890.8 |
| CO | 173 | 4230 | 1170043 | 77130 | 184519.7 |
| CT | 48 | 6121 | 1341444 | 70550.5 | 166310.6 |
| FL | 590 | 2559 | 1461448 | 86145 | 202707.9 |
| GA | 92 | 811 | 1056933 | 46484 | 118194.9 |
| HI | 30 | 5298 | 339177 | 46906.5 | 81599.68 |
| IA | 67 | 1323 | 1319984 | 62973 | 192359 |
| IL | 386 | 556 | 1477986 | 84218.5 | 231390.2 |
| IN | 195 | 570 | 1254300 | 38190 | 116039.8 |
| KS | 59 | 4826 | 776762 | 62852 | 98961.03 |
| KY | 138 | 653 | 1317446 | 48188 | 137432.1 |
| LA | 206 | 570 | 1312763 | 33726.5 | 88829.29 |
| MA | 164 | 690 | 1479830 | 76754 | 229966.6 |
| MD | 119 | 490 | 1020096 | 28554.5 | 79937.1 |
| MI | 155 | 914 | 1209326 | 79469 | 184387.3 |
| MN | 144 | 4778 | 1221273 | 69812.5 | 187366.6 |
| MO | 362 | 878 | 1240428 | 66951 | 163004.3 |
| NC | 302 | 998 | 493649 | 45251 | 89169.94 |
| NE | 12 | 5080 | 288593 | 56629 | 74226.17 |
| NH | 17 | 8255 | 309368 | 36839 | 68564.06 |
| NJ | 133 | 3958 | 1463893 | 72357 | 185233.3 |
| NM | 40 | 10932 | 458668 | 33839 | 81951.23 |
| NV | 81 | 7722 | 1029789 | 88499.5 | 179874.1 |
| NY | 452 | 1040 | 1407069 | 53982.5 | 157517.9 |
| OH | 465 | 310 | 1452591 | 68575.5 | 170077.1 |
| OK | 150 | 527 | 1087430 | 67265.5 | 179983.3 |
| OR | 87 | 7373 | 1201207 | 78974 | 154785.4 |
| PA | 417 | 618 | 1438313 | 125224.5 | 256742.6 |
| RI | 17 | 860 | 1212177 | 38843 | 108370.8 |
| SC | 87 | 2380 | 1261213 | 51164 | 145858.5 |
| SD | 17 | 10073 | 307603 | 44844 | 67958.35 |
| TN | 277 | 328 | 1387072 | 75678 | 167980.4 |
| TX | 975 | 1732 | 1489314 | 88158 | 204322.5 |
| UT | 139 | 1924 | 1080220 | 46524.5 | 108268.7 |
| VA | 180 | 1000 | 1423932 | 55517 | 165638.7 |

| | | | | | |
|---|---|---|---|---|---|
| VT | 12 | 2783 | 463805 | 21480 | 66671.75 |
| WA | 178 | 520 | 1373576 | 108189 | 204040.7 |
| WI | 151 | 7817 | 1289626 | 57484 | 176001.5 |
| WV | 43 | 6145 | 945252 | 40079 | 91512.7 |
| Total | 8,855 | | | | |

**Table 3- Individual Linear Regression Results Based on State Program Score**

| Outcome Variable | Standardized Coefficient (β) | p-value | Coefficient of Determination ($R^2$) |
|---|---|---|---|
| Total Charges | 23430.73 | <0.001 | 0.0062 |
| Length of Stay | 1.52 | <0.001 | 0.0018 |
| Number of Procedures | 0.82 | <0.001 | 0.0267 |

**Table 4- Results of the Wilcoxon Rank Sum Testing**

| Outcome Variable | No Pediatric Palliative Care Program | Presence of Pediatric Palliative Care | p-value |
|---|---|---|---|
| Median Total Charge | $57,056.50 | $79,469 | 0.008 |
| Maximum Total Charge | $1,230,851 | $1,407,069 | 0.04 |
| Median Length of Stay | 3 days | 4 days | 0.004 |
| Median Number of Procedures | 5 | 6 | 0.005 |
| Maximum Number of Procedures | 15 | 21 | 0.04 |

**Table 5- Spearman's Rank Order Correlation for Number of Inpatient Pediatric Programs In Each State**

| | Median Total Charge | Median Length of Stay | Median Number of Procedures |
|---|---|---|---|
| **Spearman's Correlation Coefficient** | 0.531 | 0.5976 | 0.4082 |
| **p-value** | 0.004 | <0.001 | 0.0081 |

**Table 6- Difference in Mean Hospital Charges for Those with and without Neuromuscular DRGs**

| | No Neuromuscular Disease | Neuromuscular Disease | p-value |
|---|---|---|---|
| **Observations** | 7614 | 832 | |
| **Mean Total Charges ($)** | 195,286.70 | 72,005.19 | <0.001 |

**Table 7- Both Multiple Regression Models Fit for Total Hospital Charge**

| | Model Not Adjusted for DRG | | Model Adjusted for DRG | |
|---|---|---|---|---|
| **Variable** | **Standardized Coefficient (β)** | **p-value** | **Standardized Coefficient (β)** | **p-value** |
| **Presence of a Pediatric Palliative Care Program** | 14377.86 | <0.001 | 14727.81 | <0.001 |
| **Length of Stay** | 7972.40 | <0.001 | 7963.17 | <0.001 |
| **Number of Procedures** | 17809.64 | <0.001 | 17624.86 | <0.001 |
| **Presence of a Neuromuscular Disorder** | | | -15839.25 | 0.006 |
| | Coefficient of Determination ($R^2$) 0.6638 | | Coefficient of Determination ($R^2$) 0.6641 | |

**Table 8- Adjusted Means Based on the Interaction Between Neuromuscular Disease and Presence of a Palliative Care Program**

| Neuromuscular Disorder | Presence of a Pediatric Palliative Care Program | Adjusted Mean Total Hospital Charge ($) |
|---|---|---|
| No | No | 179,313.70 |
| No | Yes | 195,397.60 |
| Yes | No | 168,055.30 |
| Yes | Yes | 170,929.40 |

Test for interaction p-value = 0.265

**Table 9- Adjusted Mean Hospital Charges for Only Those with Neuromuscular Disease**

| Presence of a Palliative Care Program | Adjusted Mean Total Hospital Charge ($) |
|---|---|
| No | 69628.28 |
| Yes | 76400.84 |

**Table 10- States Ranked in Ascending Order of Hospital Costs**

| State | Median Hospital Costs ($) | Pediatric Palliative Care Program Present |
|---|---|---|
| VT | 21480 | No |
| MD | 28554.5 | No |
| LA | 33726.5 | No |
| NM | 33839 | No |
| NH | 36839 | No |
| IN | 38190 | No |
| RI | 38843 | No |
| WV | 40079 | No |
| SD | 44844 | No |
| NC | 45251 | No |
| GA | 46484 | No |
| UT | 46524.5 | No |
| HI | 46906.5 | No |
| KY | 48188 | No |
| SC | 51164 | No |
| NY | 53982.5 | Yes |
| VA | 55517 | No |
| NE | 56629 | No |
| WI | 57484 | No |
| AR | 59100.5 | No |
| KS | 62852 | No |
| IA | 62973 | No |
| MO | 66951 | No |
| OK | 67265.5 | No |
| OH | 68575.5 | No |
| MN | 69812.5 | No |
| CT | 70550.5 | No |
| NJ | 72357 | No |
| TN | 75678 | No |
| MA | 76754 | Yes |
| CO | 77130 | Yes |
| OR | 78974 | No |
| MI | 79469 | Yes |
| IL | 84218.5 | No |
| FL | 86145 | Yes |
| TX | 88158 | No |
| NV | 88499.5 | No |
| AZ | 104482 | No |

| | | |
|---|---|---|
| WA | 108189 | Yes |
| CA | 112927 | Yes |
| PA | 125225 | No |

**Figure 1- Total Hospital Charges vs. State Palliative Care Score with Fitted Model**

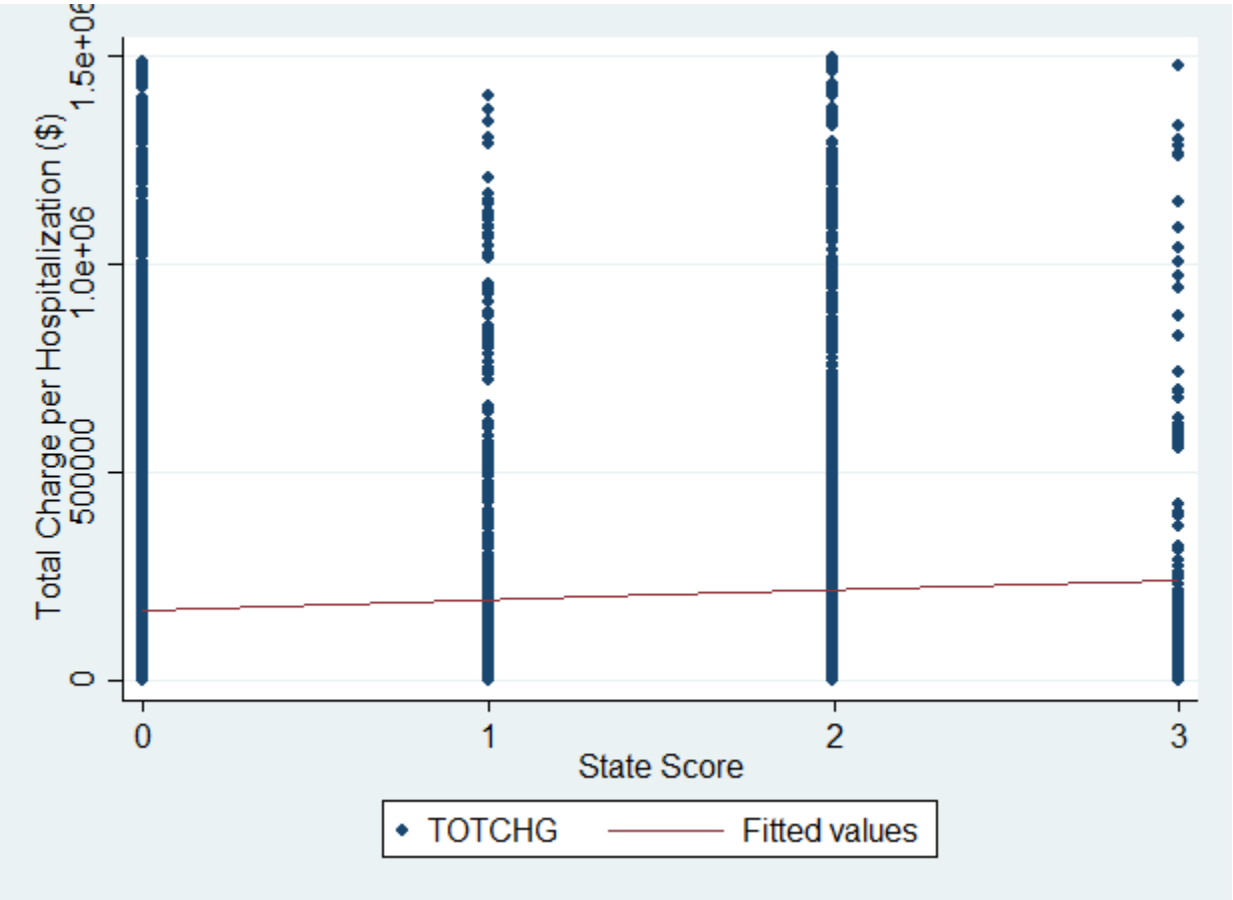


**Figure 2- Length of Stay vs. State Palliative Care Score with Fitted Model**

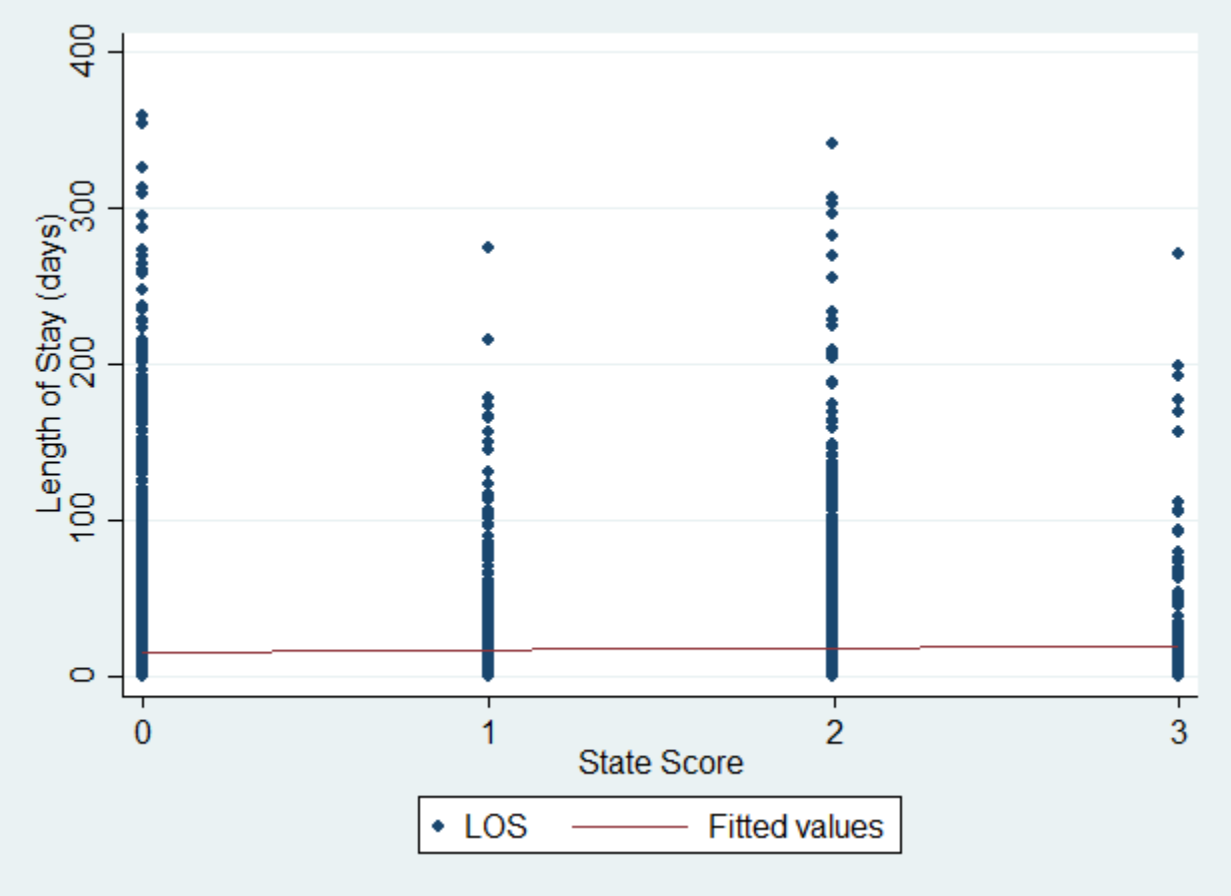


**Figure 3- Number of Procedure vs. State Palliative Care Score with Fitted Model**

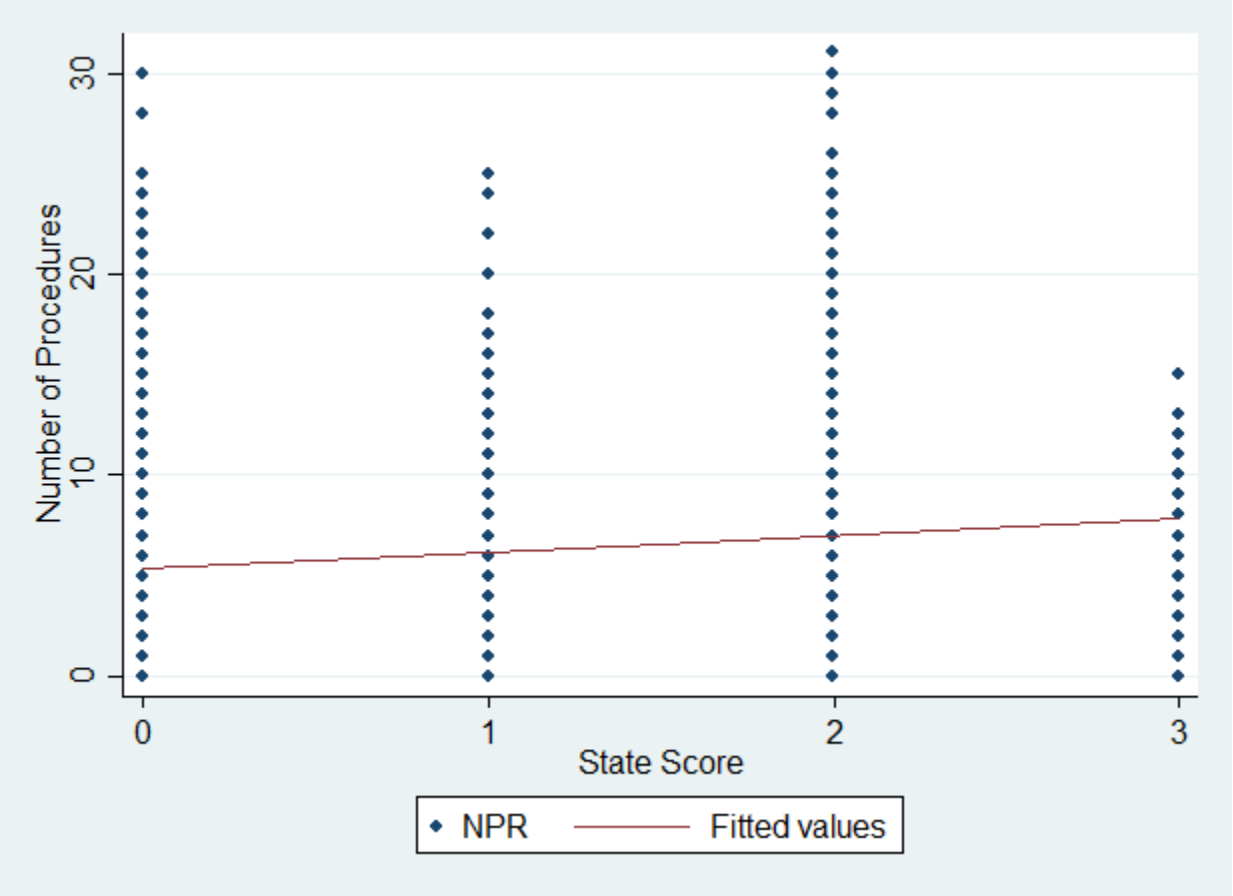


**Figure 4- Median Total Hospital Charge vs. Number of Inpatient Pediatric Palliative Care Programs from CAPC per State**

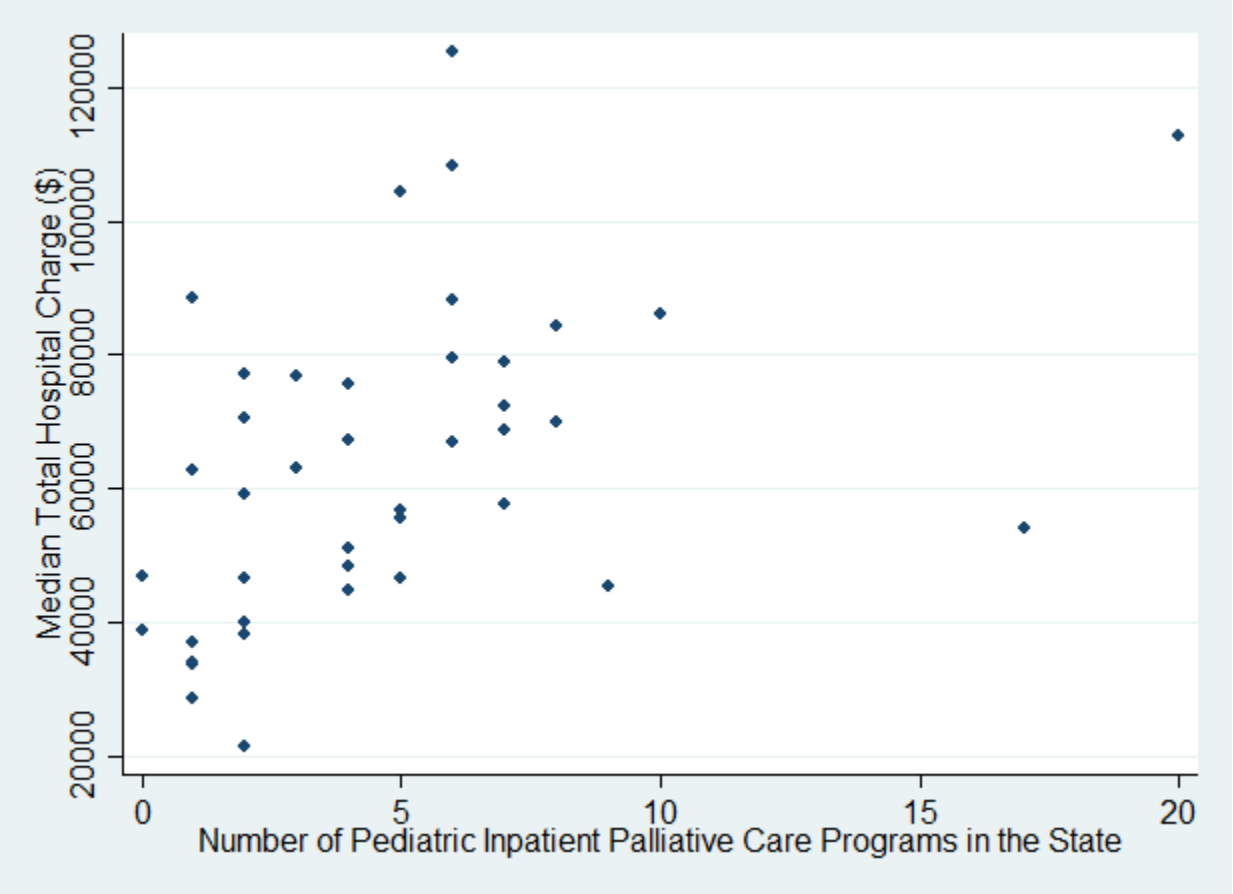


**Figure 5- Median Length of Stay vs. Number of Inpatient Pediatric Palliative Care Programs from CAPC per State**

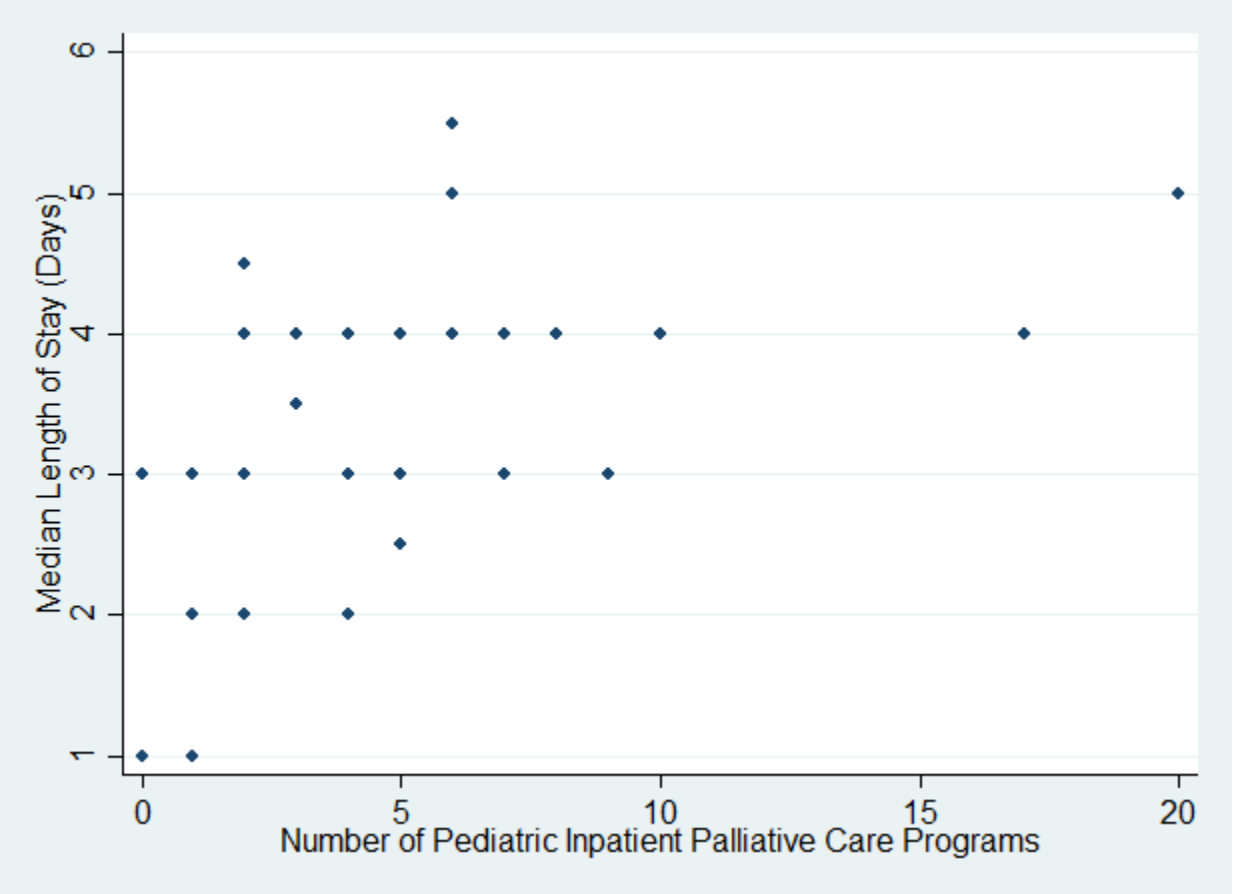


**Figure 6- Median Number of Procedures vs. Number of Inpatient Pediatric Palliative Care Programs from CAPC per State**

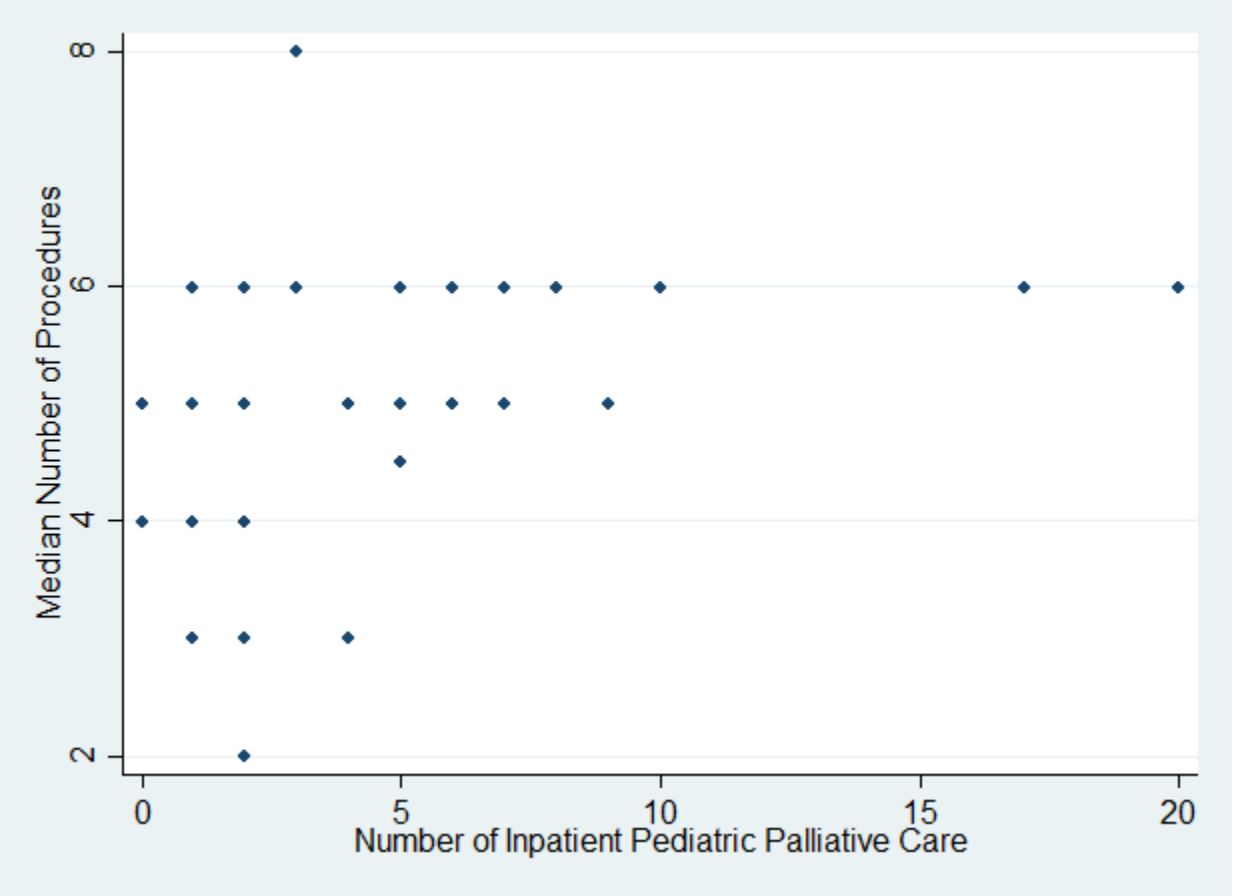
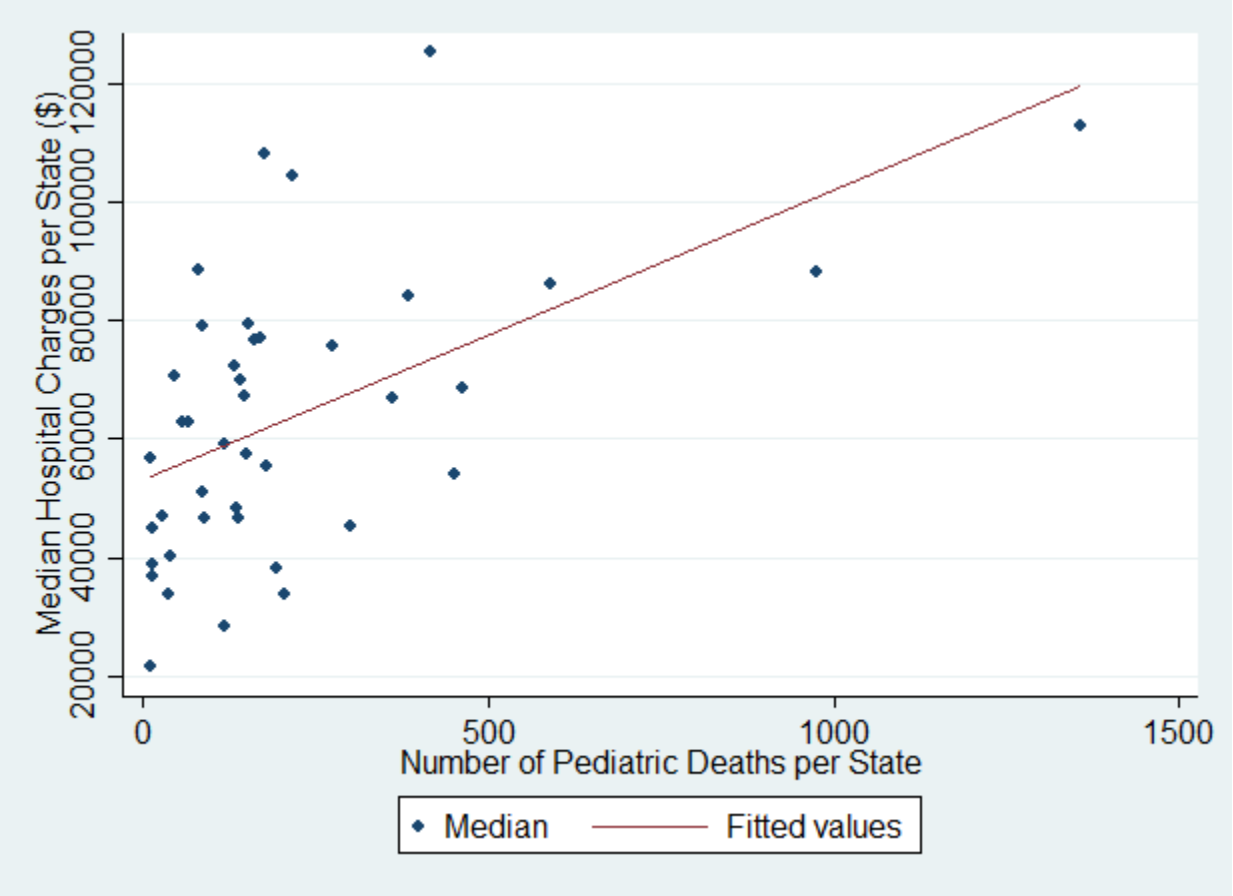


**Figure 7- Median Total Hospital Charge vs. Number of Pediatric Deaths per State**



**Appendix A- Limited Systematic Literature Review**

I conducted a MEDLINE (PubMed) search to identify previously published results from studies on pediatric palliative care and cost savings. The most recent search was conducted on October 30th, 2014. All searches were limited to publications in English. The Medical Subject Headings (MeSH) "pediatric palliative care cost savings" produced three publications. Additional searches were performed using the search phrases of "pediatric palliative care cost", "pediatric concurrent care program cost", "state pediatric palliative care program", "pediatric palliative care program cost analysis", and "pediatric concurrent care program cost analysis" in the MeSH field. A total of 90 papers resulted. The search terms resulted in a total of 10 duplicate papers. Those titles were removed and, I screened all remaining 80 paper titles, which resulted in the removal of 41 publications due to non-applicability. I then reviewed the abstracts of the remaining 39 papers, and I included the most relevant papers in the evidence table below.

The systematic review resulted in six papers with topics pertinent to the subject of my master's paper; however, there were no papers published that examined pediatric palliative care policies and their influence on health care costs. The most recent paper published on the topic was in 2012. Two groups (Gans, Kominski, Roby, et al. and Bona, Bates, Wolfe) examined their respective state's pediatric palliative care programs, but only the group from California analyzed the program based on costs per enrollee. They also looked at the change of health care expenditures before and after enrollment in California's Partners for Care (PFC) program, which showed an overall savings. Conversely, two publications from the state of Florida (Knapp, Shenkman, Marcu, et al. and Knapp, Thompson, Vogel, et al.) showed limited use of hospice care in the last year of life the pediatric Medicaid patients and those who used hospice services had increased health care costs. However, these two papers did not take into consideration palliative care programs as a whole but solely pediatric hospice services. The last

two publications in the Table A-1 examined costs of palliative care programs within their own institutions. Ward-Smith, Korphage and Hutto examined inpatient costs between samples of patients from their own pediatric palliative care program with case-matched patients who were not part of the program. They found similarities in the over total hospital costs; however the distribution of services utilized was different. They noted that those involved in the pediatric palliative care program incurred more pharmacy expenses, and those not in the program had more expenses dedicated to radiology studies. They reasoned that those in the palliative care program had more pain control medication and fewer procedures performed on them based on their observations. The final paper, which was the oldest published, compared costs of similar services provided for the same patients both inpatient and at home through the institution's palliative care program. They showed significantly lower costs for outpatient services.

Overall, there is a paucity of data examining pediatric palliative care and health care costs. The very few, limited studies or reports that are published show a cost savings when pediatric palliative care is provided comprehensively and correctly.

**Table A-1. Critical Appraisal Table of Results of Literature Search**

| Authors; Year | Study Objective | Design | Outcomes Measured | Results | Limitations/Strengths |
|---|---|---|---|---|---|
| Gans, Kominski, Roby, et al.; 2012 | Examine California's Partners for Children (PFC) program for expenditure analysis and quality of care provided. | Policy Brief- utilizing administrative costs and survey data from PFC participants. | - Administrative analysis of costs per enrollee pre and post involvement with PFC.<br>- Survey of 33 families at the time of enrollment and 6 months after participation. | - 11% reduction in spending per enrollee per month.<br>- 32% reduction in number of hospital days.<br>- Improved quality of life of families after participation with 97% reporting they would recommend PFC to a friend. | (-) Preliminary data of a 3-year pilot program before the program was complete.<br>(-) Cost data on only 74 of 123 participants.<br>(-) Satisfaction surveys on only 33 of 123 participants<br>(+) Only attempt to quantify and qualify the outcomes of PFC. |
| Bona, Bates, Wolfe; 2011 | Describe Massachusetts' (MA) experience in implementing the Pediatric Palliative Care Network (PPCN). | Retrospective and survey- Data obtained from 2010 hospice data submitted to the MA Department of Public Health and survey data from families after either 3 months in program or death of child. | - Cost of the program per year and cost per child.<br>- Family and provider satisfaction. | - 2010 Fiscal year funding to the program was $785,000.<br>- Cost per child ranged from $1,520 to $7,421<br>- 72% of families rated the value of the program to their child/family as excellent. | (-) No analysis of overall health care expenditures per child in the program.<br>(-) Survey data from only 36 of 227 families.<br>(+) First attempt to examine and report the Massachusetts experience with implementing PPCN. |
| Knapp, Shenkman, Marcu, et al.; 2009 | Describe Medicaid pediatric hospice and non-hospice users and identify factors that affect expenditures. | Retrospective, cross-sectional study using Florida (FL) Medicaid data and Florida's death certificate dataset. | - Descriptive data on hospice and non-hospice users: race, gender, rural/urban, cause of death, age, and time enrolled in Medicaid.<br>- Mean health care expenditures for hospice and non-hospice users. | - Minorities less likely than whites to use pediatric hospice.<br>- Hospice users incurred more health care expenses than non-hospice users. | (-) The study addresses hospice use, not pediatric palliative care programs.<br>(-) Using Medicaid data, it only included 1/3 of the pediatric deaths in FL. |

| | | | | | |
|---|---|---|---|---|---|
| Knapp, Thompson, Vogel, et al.; 2008 | Examine health care expenditure patterns for children in the last year of life and whether the expenditures vary based on socioeconomic factors. | Retrospective, cross-sectional study using Florida (FL) Medicaid data and Florida's death certificate dataset. | - Descriptive data on children who died in FL: race, gender, rural/urban, cause of death, age, and time enrolled in Medicaid.<br>- Health care expenditures in the last year of life. | - Infants spend an estimated $110,000 and children (>12mo) an estimated $62,000 the last year of life.<br>- Only 5% and 8%, respectively use hospice services.<br>- Minorities have increased non-hospice expenditures compared to white children. | (-) Only considers expenses in the last year of life, when these children usually receive care over their entire life.<br>(-) Only examines over all expenses and makes no attempt to determine if hospice use/expenditures saved money from decreased hospitalizations.<br>(+) First attempt to provide baseline end of life health care expenditure data. |
| Ward-Smith, Korphage, Hutto; 2008 | Compare inpatient hospital costs and identify differences in health care spending between children who received and those who did not received palliative care. | Retrospective case-control study at a children's hospital using chart review | - Total hospital costs and length of stay in the last 6 months of life.<br>- Reason for hospital charges | - Mean total hospital charges same in the 2 groups.<br>- Palliative care group underwent fewer radiology procedures but had more pharmacy expenses. | (-) Only included 9 exemplars from 133 available cases (small ample size).<br>(+) Examines hospital cost differences between children who receive and those who do not receive palliative care. |
| Belasco, Danz, Drill, et al.; 2000 | Describe a model of pediatric palliative care at one tertiary care center and retrospectively review the interventions provided and cost of care. | Retrospective case reports of 3 patients in the program | - Charges per day for equal services provided both inpatient and at home. | - Range of inpatient costs: $2300 - $8258/day<br>- Range of at home costs: $17 - $1308/day. | (-) Small sample size.<br>(+) Shows difference between home and inpatient costs of care that can be provided on an outpatient basis |

**References only used in Systematic Review:**

1. Knapp CA, Shenkman EA, Marcu MI, et al. Pediatric Palliative Care: Describing hospice users and identifying factors that affect hospice expenditures. Journal of Palliative Medicine. 2009 March; 12(3):223-9.

2. Knapp CA, Thompson LA, Vogel WB, et al. Developing a Pediatric Palliative Care Program: Addressing the lack of baseline expenditure information. American Journal of Hospice & Palliative Care. 2009 Feb-Mar; 26(1):40-6. Epub 2008 Dec 1.

3. Ward-Smith P, Korphage RM, Hutto CJ. Where Health Care Dollars are Spent When Pediatric Palliative Care is Provided. Nursing Economics. 2008 May-Jun; 26(3):175-8.

**Appendix B- Methods for Data Manipulation**

The 2009 Healthcare Cost and Utilization Project (HCUP) Kids' Inpatient Database contains information for over 3.4 million pediatric hospitalizations from 44 different states. The states not represented in the database are Alaska, Idaho, Mississippi, Alabama, North Dakota, and Delaware. The database is de-identified and contains 159 different variables for each observation. For the purpose of this project, I was interested in the information from the patients who had died while they were hospitalized. Within the database, one of the variables is whether the patient died or not during that hospitalization. I selected all of the patients who died during their hospitalization to continue the data analysis, and this resulted in 18,358 observations. Next due to the reasons stated above, all neonates were excluded from the dataset to focus purely on pediatric deaths. Neonates were identified through two different mechanisms. First, the database identifies all patients who were born at that particular hospital during that stay. All observations that were identified as hospital births were removed. They also identify all patients who had an admission type of "neonate" in a separate variable, and all of these observations were removed. This resulted in a final dataset of 8,865 pediatric deaths across the 44 included states. The state of Montana was excluded due to HCUP's regulation on the data usage. If the number of observations in any cell is equal to or less than 10, it must be excluded from the analysis. This left a total of 8,855 observations for the stratified analysis. Stata Version 13.1 was used for all statistical analysis.

Several other variables within the KID database were used. First the variable "TOTCHG" represents the total hospital charge during that hospitalization rounded to the nearest whole number. "LOS" represented the length of the hospitalization rounded to the nearest complete day, and "NPR" was the total number of procedures recorded during the hospitalization.

The "quality" of states' pediatric palliative care programs was judged based on three criteria:

1- Was there legislation enacted before 2009 that allocated state funds for a pediatric palliative care program? Or, did the state receive a 1915 Medicaid waiver to provide palliative care through a state sponsored program?
2- Was the program available to the entire state? For example, some states' programs are located only in a few sites around the state, and others are limited in the number of openings in their program.
3- Is information about the program easily available? To earn a point in this category, information about the state's pediatric palliative care program had to appear as one of the top 20 hits on Google when the search phrase "{specific state} pediatric palliative care program" or "{specific state} Medicaid pediatric concurrent care". This category was deemed important because if a state has a program but information about it is hard to obtain or entry to the program is restrictive then its utilization will be underwhelming.

A dummy variable was created to group states into two categories- ones with no state pediatric palliative care program and states that had an features of pediatric palliative care program. If the total state score equaled zero, then a zero was assigned. If the total state score was a value ranging from one to three, it was assigned a one in the newly created dummy variable.

The Center to Advance Palliative Care maintains a public database on their website getpalliativecare.org with hospitals in the United States. They identify hospitals with inpatient palliative care programs, and they note which programs accept pediatric patients. Unfortunately, they were not able to provide information on the number of inpatient pediatric palliative care programs in 2009, so for the analysis, I had to use the programs available as of their last survey in 2012. See Table 1 for the number of inpatient pediatric palliative care programs per state.

During the final stage of the analysis a second dummy variable representing neuromuscular disorders was created. A total of 17 different Version 24 DRGs exist that

classify a disease as a neuromuscular disorder. All the observations with one of these 17 DRGs were collapsed into one group creating a group of 832 observations with neuromuscular disorders. For the final two multiple regression analyses, I used this newly created dummy variable to determine the interaction between total hospital costs, neuromuscular disorder, and presence of a state palliative care program. For the final multiple regression model, only the 832 observations from patients with one of the 17 DRGs for neuromuscular disease were used.

**Appendix C- List of HCUP Data Partners**

**Alaska** State Hospital and Nursing Home Association
**Arizona** Department of Health Services
**Arkansas** Department of Health
**California** Office of Statewide Health Planning and Development
**Colorado** Hospital Association
**Connecticut** Hospital Association
**Florida** Agency for Health Care Administration
**Georgia** Hospital Association
**Hawaii** Health Information Corporation
**Illinois** Department of Public Health
**Indiana** Hospital Association
**Iowa** Hospital Association
**Kansas** Hospital Association
**Kentucky** Cabinet for Health and Family Services
**Louisiana** Department of Health and Hospitals
**Maine** Health Data Organization
**Maryland** Health Services Cost Review Commission
**Massachusetts** Center for Health Information and Analysis
**Michigan** Health & Hospital Association
**Minnesota** Hospital Association (provides data for Minnesota and North Dakota)
**Mississippi** Department of Health
**Missouri** Hospital Industry Data Institute
**Montana** MHA - An Association of Montana Health Care Providers
**Nebraska** Hospital Association
**Nevada** Department of Health and Human Services
**New Hampshire** Department of Health & Human Services
**New Jersey** Department of Health
**New Mexico** Department of Health
**New York** State Department of Health
**North Carolina** Department of Health and Human Services
**North Dakota** (data provided by the Minnesota Hospital Association)
**Ohio** Hospital Association
**Oklahoma** State Department of Health
**Oregon** Association of Hospitals and Health Systems
**Oregon** Health Policy and Research
**Pennsylvania** Health Care Cost Containment Council
**Rhode Island** Department of Health
**South Carolina** Revenue and Fiscal Affairs Office
**South Dakota** Association of Healthcare Organizations
**Tennessee** Hospital Association
**Texas** Department of State Health Services
**Utah** Department of Health
**Vermont** Association of Hospitals and Health Systems
**Virginia** Health Information
**Washington** State Department of Health
**West Virginia** Health Care Authority
**Wisconsin** Department of Health Services
**Wyoming** Hospital Association